GAE Committee H.B. 5499 Historical Preservation of Medical Records March 7th, 2016 Kristen Tierney

Dear Co-Chairs Senator Cassano and Representative Jutila and Committee Members,

My name is Kristen Tierney. I am a NAMI member and Coordinating Council member of the Keep the Promise Coalition.

I'm writing, as I did in 2014, asking you to amend H.B. 5499, AN ACT CONCERNING THE PRESERVATION OF HISTORICAL RECORDS AND ACCESS TO RESTRICTED RECORDS IN THE STATE ARCHIVES.

As this bill stands medical records of persons served by state agencies, including mental health services, would/could be made public 50 years after their death. This bill is opposed by DMHAS, CLRP, A.U. and NAMI Connecticut among other member organizations.

I strongly oppose this proposal and any language in this bill that breaks the confidentiality of people who receive mental health services through the public sector. As written, this bill would allow access to psychiatric records of individuals served in state facilities 50 years after their death, without their consent. Families would have no say in whether or not their family's psychiatric history would/could be made public.

Why is this important? One basic reason is stigma for the families and, the other is medical confidentiality. Access to care should not eliminate someone's expectations and right to retain their dignity while they receive the care we all so desperately want them to access, nor should it preclude their right to privacy and confidentiality afforded others for the same medical care. Economic status should not be the litmus test to HIPAA nor other protected information that is afforded and expected by private payers.

Lastly, what is the point of accessing this information?

• Is it scientific? Then blindly assign a number to the file.

Is it to glorify and further stigmatize or amplify the misnomer of the, statistically non-existent,
 violence perpetrated by those with mental illness?

These are important questions that need to be asked. If we, as a society, are truly interested in having those suffering from mental health conditions access, receive and continue on a path to wellness will the lifting of these expected protections become a barrier to access; an excuse, real or imagined, by those in need, to take the steps necessary to access services?

As a taxpayer, I don't feel that because a portion of my tax dollars paid for someone's care that I have a right to access their records. Nor, do I accept that argument from others or other entities.

If the remaining family can approve the record being opened that is their right, without that family approval, I strongly oppose this measure.

When we discuss parity, as in 'on equal terms', it relates not just to medical care but the protection of medical records without regard to insurance modality. The delivery mechanism of the care received (state or private) should have no bearing on matters of confidentiality of those living with any illness.

The records of those treated in the private sector are protected forever, thus making this proposal a discriminatory practice toward people served in the public sector.

I urge you to remove any sections of this bill that eliminate the protection and privacy of sensitive health care records belonging to individuals served by the state or, alternatively, to protect people's privacy regarding their healthcare records by redacting individuals' names (and other identifying information) before making data publicly available.

Thank you for your thoughtful consideration of these proposed amendments to this bill. It means a lot to those who have accessed these services and their family members.

Kristen Tierney, Fairfield, Connecticut